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Different Models of Best Practice for Transition to Adulthood and Adult Services

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Definitions

- ◆ Transition:
 - ◆ The transfer of responsibility from children's to adult services in health, social care and education;
 - ◆ A life stage: transition to adulthood encompassing a range of different processes, including leaving home, entering further education and employment, and taking more responsibility for health, nutrition and finances.

Background: Transition for YP with ASC

- ◆ Lack of statutory services to support those with HFA/AS in transition and in adulthood
- ◆ Additional difficulties coping with (multiple) transitions
- ◆ Evidence of poor outcomes for adults with autism
 - ◆ failure to realise full potential and achieve the so-called markers of adulthood: employment, independent living, fulfilling social lives and 'adult' relationships
- ◆ Existing research focuses on YP with LD

Study Aims

- ◆ To investigate transition pathways and the extent of statutory and non-statutory support during transition and into early adulthood for young people across the autistic spectrum, particularly those with HFA and AS;
- ◆ To explore young people's and parents' experiences of planning for transition and making the transition from children's to adults' services or adulthood;
- ◆ To highlight any areas of good practice.

Methods

Five research sites (local authorities) across England, 2010-11

- ◆ Interviews with managers and practitioners, n=68
- ◆ Postal survey of young people with ASC and their parents
- ◆ Interviews with young adults (18 – 24 years) with HFA and AS, n=18
- ◆ Interviews with parents/carers of young people with ASC (aged 16 – 24 years), n=36

Findings: Transition for young people with ASC and learning disabilities

- ◆ Eligible for transition service/support in all sites
- ◆ Clear transition pathways across all 5 sites
 - ◆ Children's disability team \Rightarrow transition team \Rightarrow adult learning disability team
 - ◆ Eligible for adult social care and adult mental health services
- ◆ But, query suitability of adult LD services
 - ◆ Appropriateness, awareness of sensitivities
 - ◆ Loss of a key worker at time of great change
 - ◆ Reactive, not proactive, impact on parents

Findings: Transition for those with HFA or Asperger's Syndrome

In contrast, young people with HFA and AS:

- ◆ Often ineligible for transition service/support and thus lacked a statutory transition pathway
- ◆ Ineligible for adult social care support
- ◆ Limited access to adult mental health services
- ◆ Limited community-based services
- ◆ But, some evidence of good practice...

Transition Support

- ◆ 2 sites offered only Connexions support to 19
 - ◆ In the other 3 sites Connexions offered 'adult guidance' to those with HFA/AS up to age 25
- ◆ 2 sites offered social care support:
 - ◆ C: Adolescent Outreach Team worked with many young people with HFA or AS
 - ◆ E: Transition team provided low-level service to those not open to the children's disability team, including those with HFA/AS, for YP aged 14-25.
- ◆ 1 site had a specialist Asperger's Team offering transition and post-transition support

Innovative practice/service 1

◆ Asperger's Team

- ◆ Set up in Adult Mental Health Services
- ◆ Focus on transitional issues: support/access to FE, HE, employment, independent living: “Try to bring the Asperger's context to wherever they are going”
- ◆ Open to all with HFA/AS (IQ>70)
- ◆ Origins: gap in services for young adults with AS
- ◆ 8 initial sessions, then may apply for funding to provide outreach support
- ◆ Offers training to other professionals
- ◆ Becoming a cradle to grave service

Adult Social Care

- ◆ YP with HFA/AS not eligible for adult social care in the absence of additional needs; fall in the gap between adult LD services and adult MH services
- ◆ Thus no adult services to transition to...
- ◆ YP reported feelings of isolation and anger at the lack of support from services; extra burden on parents
- ◆ Concern amongst practitioners: call for inclusive 'vulnerable adults' teams offering low-level support

“One of the saddest things is they don’t need an awful lot of money spending... that is what kills me, we’re not asking for massive great big packages. £60/70 quid a week would make all the difference”.

(Social Worker)

Adult Mental Health Services

- ◆ General under-funding of AMH services
 - ◆ Lack of funding for low-level support services
- ◆ Support from community mental health teams
- ◆ Outreach support
- ◆ Specialist Asperger's teams (2 sites)
 - ◆ **B:** Not transition focused, countywide, stretched
 - ◆ **D:** Focused on (post)transition issues, time-limited

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- ◆ Loss of MH support
 - ◆ unmet mental health support needs
 - ◆ feeling uninformed and 'let down' by professionals
 - ◆ Negative impact of interrupted MH support
 - ◆ YP feared that any progress made in children's services was in danger of being lost or reduced
 - ◆ Importance of early and adequate information
 - ◆ YP reported feeling largely comfortable with her transfer as this had been discussed with her and she knew where future appointments would be

Limited community-based services

- ◆ Patchy community-based outreach support
- ◆ ASC specific social groups and leisure activities
- ◆ YP with AS reported valuing day services and peer support opportunities/groups specifically for people with AS, helped them to feel 'normalised' – but only existed in two sites
- ◆ Funding, capacity and sustainability worries widely reported by ASC specific organisations
- ◆ Autism specific outreach service in one site...

Innovative practice/service 2

- ◆ ASC Outreach Service
 - ◆ Open to all ASC aged 16+, focus on those not open to adult services (HFA/AS)
 - ◆ Pilot - became the area's autism specific service
 - ◆ Advice, information and signposting for individuals, families, colleges, etc.
 - ◆ Wide-ranging practical support: crossing the road, going out, accessing voluntary work or college
 - ◆ Link/joint work with other agencies if eligible
 - ◆ Support services/therapies for families
 - ◆ No time limit on support/interventions

Conclusions

- ◆ Young people with HFA and AS:
 - ◆ Often ineligible for support during transition
 - ◆ Typically ineligible for adult SC and MH services
 - ◆ Invisible to strategic managers and commissioners

- ◆ What is needed:
 - ◆ Access to transition services/support
 - ◆ Better mental health support during transition
 - ◆ Provision of timely and accurate information
 - ◆ Inclusive 'vulnerable adults' teams in adult social care
 - ◆ Specialist autism/Asperger's teams in adult mental health services
 - ◆ Asperger's specific outreach services

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- ◆ Changing policy context: Autism Act and Strategy may have led to increased awareness and inclusion of those with HFA/AS
 - ◆ However, the Autism Strategy is explicitly for adults
 - ◆ Query the impact on transition services
 - ◆ Need for further research:
 - ◆ into the costs/benefits of low-level holistic support during transition and into adulthood for YP with HFA/AS
 - ◆ Into the impact and effectiveness of the Autism Act & Strategy

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- ◆ For a copy of the Executive Summary or Full Report please go to the SPRU website:
 - ◆ <http://bit.ly/TranASC>
 - ◆ <http://www.york.ac.uk/inst/spru/>

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